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Home-based family-focused rehabilitation for adolescents with severe Chronic Fatigue Syndrome.

Short title: Home-based treatment for severe CFS in adolescents.

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Conflicts of interest

TC and MB are authors of the self-help book "Overcoming chronic fatigue". TC is author of "Coping with chronic fatigue" by Sheldon press and co-author of "Overcoming chronic fatigue in young people" by Routledge.

Abstract

Aims: The purpose of this paper is to describe and evaluate a home based, family-focused rehabilitative approach for severely affected housebound adolescents with Chronic Fatigue Syndrome (CFS). The main aims were to facilitate a return to school, improve physical functioning, reduce fatigue and assess any adverse effects of the intervention.

Methods: Six housebound adolescents aged 11-18, diagnosed with CFS by a Paediatrician, were assessed and treated at home by an experienced cognitive behaviour therapist. Outcomes were assessed 12 months after discharge from treatment.

Results: At 12 months follow-up all patients had returned to either school or college, and physical functioning had improved in most of the patients. Fatigue had reduced in some. No adverse effects of the intervention were reported.

Conclusion: Severely affected adolescents with CFS showed improved physical functioning and social adjustment after a home-based rehabilitative approach. Although several patients showed improvements in physical functioning, they did not all show substantial improvements in fatigue. At this crucial stage of development, it is important to offer young people and their parents hope by stating that improvement is possible.

Chronic Fatigue Syndrome (CFS) is characterised by chronic disabling fatigue in the absence of an alternative diagnosis (Prins, Van der Meer, & Bleijenberg, 2006). The prevalence of CFS in community samples of adolescents ranges from 0.19% to 0.6% (Chalder, Goodman, Wessely, Hotopf, & Meltzer, 2003; Rimes et al., 2007; Taylor et al., 2003). Although the prognosis of CFS in adolescents is relatively good (Joyce, Hotopf, & Wessely, 1997; Norris et al., 2017; Rimes, et al., 2007), evidence from tertiary care suggests that a substantial minority of individuals remain disabled for long periods of time (Rangel, Garralda, Levin, & Roberts, 2000). Individuals with CFS may become housebound due to the severity of their symptoms (Garralda and Chalder, 2005). However, many are not receiving help. Uncertainty about what to offer and fear of causing harm may play a part in this.

To date, three controlled studies have shown cognitive behaviour therapy (CBT) to be effective in reducing fatigue and disability in ambulatory adolescents with CFS (Stulemeijer, de Jong, Fiselier, Hoogveld & Bleijenberg, 2005; Chalder, Deary, Husain, & Walwyn, 2010; Nijhof, Bleijenberg, Uiterwaal, Kimpfen, & Van de Putte, 2012). However, the management of severely affected adolescents with CFS has been somewhat neglected. This study examined whether home based family-focused rehabilitation over many months improved health outcomes for adolescents with severe CFS and considered whether there were any adverse effects of treatment.

Methods

Participants

Participants were patients aged 11-18 years, diagnosed with CFS by a Paediatrician.

They were referred to a specialist service for adolescents with CFS based in secondary care in a hospital trust in the UK. The clinician who assessed and treated the participants of this study was a highly experienced therapist and part of a team of clinicians specialised in the treatment of CFS. This team received regular group supervision from a consultant in Child and Adolescent Psychiatry. Due to the severity of the fatigue and the complexity of the cases, it was essential that the treatment was delivered by an experienced therapist working for a specialist CFS service. The service accepts

referrals from Paediatricians, GPs and CAMHS. Patients who were unable to attend a hospital appointment due to the severity of their symptoms were assessed at home by the therapist, in order to verify that they met diagnostic criteria for CFS. All participants met Oxford diagnostic criteria for CFS (Sharpe et al., 1991). The therapist also determined whether a family-focused rehabilitative approach, in the form of CBT, was suitable for the patient. Consent was obtained from study participants.

Family-focused approach.

The main aim of treatment was to help the patients to increase their level of functioning and reduce their fatigue with the aim of recovery and a return to school / college when possible. In order to achieve this goal, therapy time was divided between the patient alone, parent(s) alone and the family altogether. Parents were seen individually as well as with their daughter/son so that they could discuss any of their concerns about treatment. This set a positive tone for treatment. Collaboration between therapist, patient and family was key to ensure good communication and an understanding of any concerns that needed to be addressed such as worries about a return to school. In some cases the therapist was met with some resistance, but at the start, the therapist made clear to the family that the treatment was likely to be challenging, particularly if a previous treatment had been unsuccessful and they were fearful or sceptical about the treatment approach. Where any problems or difficulties were apparent during sessions, they were discussed with the family to facilitate a solution. A shared formulation was developed and clear goals were agreed upon so that a treatment plan could be followed. Flexibility in the treatment approach was crucial. A priority throughout sessions was to instil a feeling of hope even at difficult times.

Sessions ranged in length between one and two hours. Sessions were conducted in a flexible manner to ensure that the needs of the patient and parents were met. The initial session was focused on developing a shared understanding of factors that may have contributed to the onset of the problem and factors that may be perpetuating or maintaining it. A treatment manual was given to the young person (Lloyd, Chalder, Sallis, & Rimes, 2012; Rimes & Chalder, 2015) and they were asked to

complete sleep and activity diaries with help from parents. At the second session, information about patterns of activity, rest and sleep, gained from their diaries, was used to form a programme of consistent activity and rest. A range of sleep strategies were discussed that included a regular getting up time (or sitting up in bed) and stimulus control exercises to associate bed with sleep rather than being awake. They were encouraged to reduce or eliminate naps in the day. Adolescents identified specific goals to work towards during treatment.

During subsequent sessions, levels of activity were gradually increased as tolerance allowed. Fears about symptoms and thoughts that were impeding change were addressed using behavioural experiments, problem solving and thought challenging.

Other worries that in some cases contributed to low mood or anxiety were addressed. These included worries about reintegrating back into school, the effects of their illness on the family as well as making new friends and how to approach exams and school trips. In some cases, unhelpful beliefs around “not being good enough” due to not being able to perform at their usual standard were discussed. Relapse prevention, management of setbacks and ways to build on progress were discussed before discharge.

Discussion with parent(s) involved an overview of how things had been between sessions. Any difficulties that had arisen were problem-solved, and advice to parent(s) was given, as appropriate, about how to manage an increase in their child’s symptoms. Time was spent discussing how to set small goals for the parents and to gradually reintroduce activities into the parents’ lives, such as work, exercise and social activities as their child became less dependent on them. In some cases, concerns about other family members were discussed. It was suggested that two mothers seek professional help for their own distress.

The young person and their parent(s) were usually seen together for a few minutes at the end of every session; this gave everyone the opportunity to talk about goals that had been agreed for the coming

weeks. In addition, any problems that had arisen between sessions were discussed with an agreement of how to move forward. The therapist was in contact by phone, email, letter and in person with other professionals involved in the young person's care, e.g. physiotherapists, tutors, GPs, Paediatricians, school nurses and teachers. This ensured that the young person's needs were being met and that they were receiving consistent advice. The therapist was flexible in terms of how many sessions were offered as it was recognised that longer term help may be needed for severely affected patients.

Outcome measures.

As well as school attendance, the following self-rated questionnaires were completed, prior to initial assessment, pre-treatment, post-treatment and at 3, 6, and 12 months follow-up:

Main outcomes.

Fatigue. This was assessed using the Chalder Fatigue questionnaire (Chalder et al., 1993; Cella & Chalder, 2010). This 11-item measure of physical and mental fatigue symptoms is rated on a four option continuum from "less than usual" to "much more than usual". The eleven items are totalled to give a score out of 33. This questionnaire has been used in previous CFS treatment trials and is reliable and valid (Cella & Chalder, 2010).

Social adjustment. This was measured using the school and social adjustment scale - adapted from the Work and Social adjustment scale (Mundt, Marks, Shear, & Griest, 2002). This 5-item questionnaire, which has been adapted for use in adolescents, assesses the degree to which fatigue interferes with the young person's ability to go to school and engage in social, private and leisure activities and relationships. Impairment in each area is measured on a Likert scale from 0 indicating "not at all impaired" to 8 "very severely impaired", with a total score of 40. The scale has been shown to be reliable (Cronbach's alpha 0.7-0.9) and valid in a CFS population (Cella, Chalder, & Sharpe, 2011). The scale will be referred to as the school and social adjustment scale in this paper.

Physical functioning. This was measured using the SF-36 physical functioning subscale (McHorney et al., 1993; Ware and Sherbourne, 1992). Participants are given a number of items and asked to rate the extent to which their health limits them carrying out certain activities such as

climbing up a few flights of stairs, bending down or lifting things. Each item has three possible response options: 'Yes, limited a lot', 'yes, limited a little', and 'No not limited at all'. A six-item version of this scale was used. The six items were summed to get a total score out of 60, which was then converted into a percentage. A higher score indicates better functioning.

Additional outcomes.

Anxiety. This was measured using the Spence children's anxiety scale (SCAS; Spence, 1998) which has 44 items. Participants rate each item on a scale ranging from 0 (never) 3(always) in terms of how often each item happens to them. The 38 anxiety-present items are summed to get a maximum score out of 114. A higher score indicates more anxiety.

Low mood. This was assessed using the 18-item depression self-rating scale for children (Birleson, 1981) in which participants were asked to rate how they felt during the past week and to what extent each item applied to them. There were three response options: never, sometimes and mostly. Each item received a score between 0 and 2. For the majority of items, a higher score indicated more depression. However, some items were scored in the opposite direction. A total score was calculated by summing the item scores.

Behavioural problems. These were measured using the strengths and difficulties questionnaire (Goodman, Meltzer & Bailey, 1998): this questionnaire can be used for screening for behavioural problems or psychiatric disorder. The questionnaire consists of subscales relating to emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The total difficulties score is calculated by summing the scores for the first four subscales.

Global outcome. (Guy, 1976). This global improvement scale was rated by the young person and their parents. Response options range from "very much better" to "very much worse". Satisfaction with treatment was rated on a 7 point scale from "very satisfied" to "very dissatisfied".

Statistical analysis.

Data were summarised using descriptive statistics, including measures of central tendency.

Results

Demographic characteristics of the sample can be seen in Table 1. The sample comprised of 4 boys and 2 girls whose ethnicity was Caucasian. Onset of illness was between 10 and 16 years with a mean age of 11.5 years (SD 2.3). The duration of illness before assessment ranged from 1.6 to 4.8 years with a mean of 2.7 years (SD 1.5).

Five out of the 6 adolescents spent the majority of the day either on a sofa or in bed.

All adolescents completed treatment. The number of treatment sessions given during the treatment phase varied between 23 and 51 with a mean of 33 sessions. The length of time over which treatment took place was between 16 and 35 months with a mean of 24 months. All patients had follow-up appointments at 3, 6, 9 and 12 months after the end of treatment. Measures were completed at each time point except 9 months.

Improvement was seen on all outcomes at 12 months follow up (see Table 1; Figure 1); this is 12 months after treatment finished. Self-rated measures were missing from one patient at discharge from treatment although he had returned to school. Individual patient scores for the main outcomes throughout the course of treatment are shown in table 2.

Benefits were also seen in the parents, including four out of six mothers returning to part-time employment and previous social activities.

[Insert Tables 1 and 2 here]

[Insert Figure 1 here]

Global improvements

At 12 months follow-up, three patients said they felt very much better, one reported they were much better and one a little better. Three parents reported their child was very much better, two rated that they were much better and one about the same.

Satisfaction with treatment

At 12 months four patients were very satisfied with the outcome of treatment and one was moderately satisfied. Likewise, five parents were very satisfied with the outcome of treatment at 12 months and one was slightly satisfied.

Long-term follow up

Two of the six patients completed questionnaires approximately 6-8 years after treatment had ended. The first reported that they had completed an A-level equivalent course and was now doing a university degree. The second reported that they were living independently from their family, had completed an undergraduate degree and had made friends, leading to less social isolation. However, the latter patient had had half-hour, monthly telephone support from one of the authors (a cognitive-behaviour therapist) over the past year.

Discussion

A home-based family-focused rehabilitation programme based on cognitive behavioural principles substantially improved functioning in all six patients at discharge from treatment, and this was maintained at 12 months follow up. Six of the patients returned to education on a part-time basis, one of whom was attending an internet-based school and one had started a part-time college course. Global ratings by patients and parents were positive. None of the patients or their parents felt that they were worse or were dissatisfied by treatment. No adverse effects of treatment were reported. Increases in fatigue were not attributed to the approach.

The findings of this study are in keeping with research which shows that cognitive-behavioural therapy can lead to reduced fatigue and improved functioning in adolescents with CFS (Chalder et al., 2010; Chalder, Tong & Deary, 2002; Lloyd et al., 2012; Stulemeijer et al., 2005) and that improvements can be maintained at follow-up (Lloyd et al., 2012; Knoop, Stulemeijer, de Long, Fiselier, & Bleijenberg, 2008). The results also support the findings of case reports which have shown that family-focused cognitive-behavioural treatments can help to improve fatigue and/or functioning

in adolescents with severe chronic fatigue or CFS (Burgess and Chalder, 2011; Graham, 1990; Wachsmuth & Macmillan, 1991).

It is important to note that change was not linear. Individual change over time was varied, with some individuals' fatigue levels increasing. Improvements in physical functioning and social adjustment did not necessarily match changes in fatigue. This supports previous research where adolescents who report themselves as recovered still continue to experience fatigue symptoms (Sankey, Hill, Brown, Quinn & Fletcher, 2006). One study found that in comparison to healthy controls, adolescents with CFS had unrealistic expectations of normative levels of fatigue (Garraida & Rangel, 2001). Therefore it is possible that participants were experiencing normal levels of fatigue compared to the general population, but that their expectations of fatigue were still lower than this. The aim of the current treatment was to help adolescents to deal with normal levels of fatigue that is experienced on an everyday basis. The findings suggests that in some participants, the ability to manage and tolerate fatigue improved.

The findings also showed that on average, anxiety increased during treatment. This may have been due to the adolescents resuming everyday activities. For example, reintegrating into school life can be a source of anxiety. In addition, adolescents with a history of severe CFS may be vulnerable to developing psychiatric disorders such as anxiety and depression (Garraida, Rangel, Levin, Roberts, & Ukoumunne, 1999). It has been suggested that schools should be involved in the process of rehabilitation so that adolescents can receive the appropriate support as well as minimising the educational disadvantage and social isolation caused by school absence (Sankey et al., 2006; Tillet, Glass, Reeve & Burt, 2000). It should be noted that even though anxiety increased, mean scores for anxiety and depression did not reach clinical cut-off thresholds, and this was the case throughout treatment.

It is possible that the improvements seen in this study were spontaneous and that the fatigue resolved during the natural course of the illness. However given the severity of the illness and the length of

time that the adolescents had been house-bound, this explanation is unlikely. This requires further investigation. Most research on prognosis in adolescents with CFS has been conducted on those who have accessed treatment in specialist services. There are very few community-based studies. One longitudinal study of 35 participants based in the USA followed a group of children and adolescents with CFS over an average period of 13 years. At follow up (approximately 13 years after diagnosis), 37% of participants reported that their illness had resolved, whereas 42.9% felt well but not fully recovered (Bell et al. 2001). In a large population-based study in the UK, Norris et al. (2017) found that 75% of adolescents with chronic disabling fatigue (CDF; the authors' proxy for a medical diagnosis of CFS) at age 13 no longer met criteria for CDF by the age of 18. These findings are promising. However, to our knowledge, there is no current existing evidence about the natural course of untreated severe CFS in adolescents.

Although an analysis of cost-effectiveness was not undertaken in the current study, it could be argued that the cost of treatment is low compared to the projected cost of untreated severe and chronic CFS in terms of increased healthcare use as well as lost employment of parents who stop working to care for their children with CFS.

A key limitation of case series is that the findings are based on a small sample size within an uncontrolled study design. Moreover it was not appropriate to conduct inferential statistical tests such as t-tests due to data not meeting the required assumptions for these tests, as well as a lack of statistical power. The sample consisted of patients who were being treated within a specialist service and therefore may not have been representative of patients with severe CFS, many of whom do not have access to treatment. Equally important is the fact that the approach was offered by an experienced team. Due to these caveats the results should be interpreted with caution.

Further research is needed into treatments for severe CFS in adolescence. It is imperative that this group of disabled adolescents and their families are offered hope of improvement at such a crucial stage of their development. It is important that therapists who work with this group of patients with

complex needs are committed to them over a long period of time as change can be very gradual and a number of set-backs can be encountered along the way. Therapeutic nihilism, the idea that nothing can be done, may act as a self- fulfilling prophecy for the young vulnerable person and the health professional.

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Table 1. Mean scores and standard deviations for main outcomes over time

Mean score (SD)	Baseline N=6	Post-treatment N=5	3-month follow up N=6	6-month follow up N=6	12-month follow-up N=5
Chalder fatigue scale score	26.17 (4.75)	13.00(11.53)	14.00(6.48)	18.00(7.40)	19.4(9.81)
Mean social adjustment score	33.33(10.63)	17.20(6.26)	15.60(10.38)	12.83(7.55)	16.00(12.63)
Physical functioning score	22.22(20.86)	66.67(11.79)	69.44(13.61)	73.61(12.27)	76.67(18.07)
Percentage school attendance	2.28 (5.59)	60.54(36.79)	89.86(19.68)	68.49(42.52)	64.11(49.68)
Mean anxiety score	22.25(8.99)	26.00(8.54)	17.75(12.0)	12.50(0.71)	24.50(16.26)
Mean depression score	13.67(1.53)	11.50(4.95)	8.60(2.88)	10.50(3.69)	10.25(4.99)
SDQ total difficulties score	10.00(4.24)	12.67(4.16)	10.00(3.37)	11.80(3.42)	12.00(5.70)

Table 2: Individual scores for the three main study outcomes.

		Patient					
		P1	P2	P3	P4	P5	P6
Outcome	Time-point						
Fatigue	Baseline	29	33	25	19	27	24
	Post-treatment	22	-	-	0	17	0
	3-month follow up	21	-	6	17	-	12
	6-month follow up	23	30	10	17	16	12
	1 year follow-up	29	29	8	20	11	-
Physical functioning	Baseline	0	0	25	50	16.67	41.67
	Post-treatment	58.33	66.67	83.33	58.33	-	-
	3-month follow up	66.67	58.33	83.33	50.00	75.00	83.33
	6-month follow up	58.33	66.67	91.67	75.00	66.67	83.33
	1 year follow-up	50	66.67	91.67	83.33	91.67	-
Social adjustment	Baseline	40	40	40	24	40	16
	Post-treatment	20	24	20	14	8	-
	3-month follow up	21	25	23	-	2	7
	6-month follow up	14	23	15	17	3	5
	1 year follow-up	28	30	8	13	1	-

Figure Legends

Figure 1: Change in mean fatigue and social adjustment scores over time

Figure 1

